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PROBLEMS IN DETERMINING THE EXTENT OF BLINDNESS

By EVELYN C. McKAY

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PROBLEMS IN DETERMINING THE EXTENT OF BLINDNESS

By EVELYN C. MCKAY

Work for the blind in the United States has just celebrated its hundredth anniversary and at present there are more than a hundred well-established state and voluntary agencies for the blind in this country. Yet in spite of general recognition of the importance of blindness, no one can say with any degree of certainty what is the extent of blindness. The purpose of this paper is to point out some of the reasons why this is so, and to indicate briefly some of the measures which are being taken to solve the problems involved.

Since 1830, the Federal Bureau of the Census has included in its decennial enumeration a census of the blind. These enumerations formed an essential basis for the establishment of agencies for the blind in various states and cities, and particularly for securing of state funds to carry on such activities.

But as these agencies increased in number, and particularly as greater efforts were made to reach the blind in their homes instead of concentrating on those who came to the institutions, it became apparent that the Census figures, useful as they were for certain purposes, were not complete. This incompleteness of enumeration was recognized by the Census authorities themselves and they estimated that while only 52,567 blind persons were reported in the 1920 census, the total was probably 75,000. Various workers for the blind estimated that the total number was possibly 100,000.

Nor was the incompleteness of the count the only fault in the data. It was impossible to determine whether the blind persons reported in the census were representative of the blind population as a whole. It was conceivable that the blind in urban areas might have been more easily located than the blind in isolated districts, or that the young blind attending special schools were more completely reported than the adult blind living in their homes, etc.

These defects in the data were due to two factors: First, certain problems inherent in the condition of blindness itself; and second, to problems inherent in periodic enumeration as a method.

In the first place, "blindness" is a vague term and includes many degrees of visual defect. The definition of blindness used in the 1920 census was "inability to read even with the aid of glasses." While this is satisfactory for general purposes, it is liable to variation in application at the hands of enumerators. Moreover, certain eye defects are of such a nature as to render the individual unable to carry on an

occupation for which eyesight is essential, even though he may retain enough vision to read.

Another difficulty is that many persons are unwilling to admit that there is blindness in the family and therefore do not report it.

The most important reason for the incomplete reporting, however, probably lies in the comparative rarity of blindness. The highest estimates so far arrived at would seem to indicate that the incidence of blindness in the United States is not more than one per thousand, and since the enumerator encounters a case so infrequently, he is likely to give up inquiring for it.

The various agencies for the blind, particularly those supported by State funds, have sought to secure more adequate figures by establishing so-called "registers of the blind," on which the names and addresses of all blind persons known to live within the given area are recorded, together with certain important facts regarding them. These registers have certain advantages over the Census enumeration in that:

1. The agency for the blind has definite services to offer, and therefore there is an incentive for the blind person to report his blindness.
2. The enumeration extends over a longer period of time and in many states is a more or less continuous activity.
3. The enumeration or registration is done by persons whose chief interest is the blind, and who are more or less familiar with the conditions of blindness.

Investigation, however, shows certain serious defects in the existing registers, namely:

1. The registration is done by persons who are for the most part unacquainted with statistical methods.
2. In all too many cases, the registration is based on the judgment of the field agent or on the report of the blind person, and not on actual tests of vision.
3. The agency for the blind is primarily concerned with rendering service and consequently blind persons who are not in need of its service are likely to be overlooked.
4. There is in most states no adequate machinery for keeping the register up to date.

Even if we were prepared to say that, in spite of these weaknesses, the existing registers in individual states were sufficiently complete and accurate to make analysis of the data valuable, a comparison of the registers of various states shows that there is little uniformity in their definitions of blindness, in their methods of registration, or in the classifications they use in analyzing the data collected. It is therefore impossible to make comparisons between one state and another or to

compile from these registers any accurate figures on blindness in the United States as a whole.

These are some of the reasons why no accurate statistics on the extent of blindness are available. Workers for the blind and others interested in social problems have long felt the need of more adequate data on the subject, and in 1929 the American Foundation for the Blind, a national organization for research in problems of blindness, and the National Society for the Prevention of Blindness, a national organization for preventive work, united in calling an informal conference to consider the matter of better statistics of blindness. Those attending the conference included statisticians, representatives of the medical profession, workers for the blind, and social workers from other fields. Following this conference, a working committee (which later became known as the Committee on Statistics of the Blind) was formed for further consideration of the problem. The second part of this paper, which will deal with some of the measures that are being tried in an effort to develop better statistics of blindness, will be based largely on the work of the Committee during the past two years.

The problem of the extent of blindness can be resolved into two questions: What is blindness? and, How can the blind be enumerated?

First, as to What is blindness? The definition employed in the 1920 census has already been mentioned—"inability to read even with the aid of glasses." As has also been already indicated, workers for the blind felt that this did not entirely fit their needs since some of the persons under their care were for vocational purposes blind, yet retained enough vision to pass the reading test. Physicians, on the other hand, were accustomed to refer to blindness in terms of the amount of vision remaining, as shown by their measurement charts, and employed varying terminologies in recording their findings.

In 1927, two professional organizations in work for the blind, namely, the American Association of Workers for the Blind and the American Association of Instructors of the Blind appointed a joint committee to draw up a definition of blindness which would be acceptable to educators, ophthalmologists, and workers for the blind. The report presented offered three definitions acceptable respectively to each of the three groups named. Excellent as these definitions were, they were somewhat unsatisfactory for statistical purposes.

One of the first tasks of the Committee on Statistics, therefore, was to develop some statistical basis for classifying persons as "blind" or "not blind." It was felt that no single definition was likely to meet with the approval of all groups concerned, but that some subdivision of the whole range of blindness might be effected so that the data of one agency might be compared with those of another. It was also necessary to develop some means by which the reports of the ophthal-

mologists, who were likely to use different terminology and different systems of measurement, could be expressed in common terms.

The Committee has worked out a table for this purpose. The first step was to divide the blind into groups according to "amount of vision remaining," selecting groupings which, according to experienced workers for the blind, had significance in determining the vocational possibilities of blind persons. The upper and lower limits of these groups were then expressed in terms of Snellen measurements of vision, the system of vision-testing which is in general use in this country. The groups selected were:

1. Totally blind or having "light perception" only (0 to 2/200)*
2. Having "motion perception" and "form perception" (2/200 to 5/200)
3. Having "traveling sight" (5/200 to 10/200)
4. Able to read large headlines (10/200 to 20/200)
5. "Borderline" cases (20/200 or more but not sufficient for use in an activity for which eyesight is essential).

Since it is not always possible to arrange for a blind person to have an eye examination, a set of tests for the use of lay workers was added, these tests corresponding as nearly as possible to the groupings already set up.

This chart has been worked out with the help of several ophthalmologists and workers for the blind and has already been tried out on several groups of records with satisfactory results, but it is still subject to modification by the various professional organizations to whom it is to be formally submitted. Such a chart will make it possible to compare the registers of the blind in different states which have hitherto been incomparable because of varying definitions of blindness.

As to the other question. How can the blind be enumerated? Some of the difficulties involved in locating all the blind people in a given area have already been mentioned, and it has been pointed out that the existing registers of the blind are probably somewhat inaccurate.

One of the members of the Committee suggested that it would be desirable to make intensive surveys in certain limited areas, to determine the degree of completeness of the existing registers, and a member of the Committee who is head of the state work for the blind in Connecticut, volunteered to make the first studies. It was agreed that as many groups in the community as possible should be reached in an effort to tap every available source from which names of blind individuals might be reported. Records were kept of the returns from each group so that the study served also as a test of the comparative efficacy of the various case-finding methods.

* Snellen measurements of visual acuity.

Two areas, one rural and one urban, were selected for the study, each with a population somewhat over 100,000 according to the 1930 census.

The various methods used for securing new names were as follows:

1. Letters to blind persons already on the register requesting them to report names and addresses of all blind persons they knew of. (These letters also served as a check on the accuracy of the existing registration).
2. Similar requests to users of electricity in the selected areas, these requests being enclosed in the monthly statements sent out by the company. Over 75,000 patrons were reached in this way.
3. Requests to physicians.
4. Requests to clergymen.

It was felt by the Committee that the schools might have been another fruitful source, but since for administrative reasons it was necessary to make the study during the summer months, the schools had to be omitted.

The returns were carefully checked against the existing register and against each other and all duplicates eliminated. Each blind person reported was then visited by an experienced field agent and certain data were secured. This visiting led to further eliminations of names.

It was found that 771 names were reported from various sources. Of these, 512 or about 66 per cent came from the electric service patrons. When it is remembered, however, that more than 75,000 patrons were solicited, and that these returns represent less than eight-tenths of one per cent of the total, it becomes apparent that this method is not economical of labor.

The next most fruitful source was the blind already registered—these reported 79 names. Physicians reported 31 and clergymen 27.

To test the completeness of the survey, a re-canvass of certain towns was made, and 11 new names were added to the list; 112 names had already been reported from these areas so that the results of the re-canvass represent an increase of 10 per cent. Because of certain factors in the re-canvass, this cannot be taken as a representative figure, but it suggests that even the extensive methods used were somewhat inadequate.

Of the 782 names reported, 621 were discarded as being "not blind," blind in one eye only, duplicates, "not located," or living out of district.

This left 161 names, or about 21 per cent to be added to the register.

Of the 372 names on the register at the close of the survey, 211 had been on the register at the beginning. This gave a rate of .915 per 1,000 of the general population. Since the highest estimates made suggested 1 per 1,000 as the probable incidence of blindness, it might have been supposed that the original register was more than 90 per cent complete.

Nevertheless, when the 161 new names were added to the register, making a total of 372 names, it became apparent that the original register had been only 57 per cent complete. In justice to the Connecticut organization it must be added that the definition of blindness used in the study was somewhat more liberal than the one formerly in use, and this accounts for part of the increase in names. But even if the more restricted definition is used and the "borderline" cases (which numbered 85) are omitted, the original register is found to be only 79 per cent complete.

Unfortunately, no record was kept of cases on the original register which during the survey were found to be obsolete (that is, dead, moved out of the area, or regained sight). That there were some such is known and this indicates a further inaccuracy in the original register.

The conclusions drawn from this study were as follows:

1. That existing registers of the blind are probably not complete or up to date.
2. That there is need for further trial and evaluation of case-finding methods.
3. That there is need for the development of better methods of current registration and of eliminating "dead records."

The Committee hopes to follow the Connecticut study by studies in selected areas in other states, with the two-fold purpose of testing the completeness of the registers and of testing and of evaluating case-finding methods by which registers may be improved. There still remain, however, other problems to be solved before adequate statistics will be available. This report is a report on problem and method rather than a report of accomplishment.

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